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Understanding family carer experiences of advanced dementia caregiving in India: towards a vision for integrated practice.

Abstract

Purpose: Many individual and family hardships are associated with poorly understood palliative care needs arising from advanced dementia within India. The aim of this project, was to explore the experiences of people in India affected by advanced dementia and to shape educational approaches for practitioners and the local community.

Methodology: Three focus groups with family carers of people (n=27) with advanced dementia were undertaken with local communities in South India. One focus group was carried out in English and two in the local language (Kannada) and translated to English.

Findings: The findings of the focus groups are presented in four themes, conditions of caring, intersecting vulnerabilities, desperate acts of care and awareness of education and training needs. These themes highlight the challenges faced by family carers of people with advanced dementia and describes the potential harm, abuse and poor mental wellbeing facing both the person with dementia and the family carer as a result of their situation.

Research implications: There is a need to explore ways to ensure inclusivity and sensitivity in the research process and enable equal participation from all participants.

Practical implications: The findings highlight a lack of support for family carers of people with advanced dementia and demonstrates the need for dementia-specific integrated and palliative care approaches in India.

Originality/value: This paper provides insight into the experiences and challenges facing family carers of people living with advanced dementia in India to shape practitioner education in a way that will underpin effective dementia-specific palliation and integrated services.

Keywords:

Advanced dementia, family carers, palliative care, integrated care, India, focus groups

Introduction

Dementia is a global health priority, with approximately 47 million people worldwide living with dementia. This figure is expected to increase to 75 million by 2030 (Prince, 2015). As such, there is an urgent need to respond to the care and support needs of people with dementia and their families through the development of prudent policies and integrated practices (Tolson et al. 2016). Globally, 32 countries and territories have developed dementia strategies in response to the priority areas of the WHO Global Action Plan on the public health response to dementia 2017-2025 (Alzheimer Disease International, 2018). However, in countries such as India, which has rapidly changing population demographics and an increasingly ageing population, the impact of dementia has not been fully considered (Sinha, 2011).

There are currently an estimated 4.1 million people living with dementia in India, and this figure is set to treble by 2050 (Shaki et al., 2010). Health is a state subject meaning that the 35 individual states undertake planning and development for people with dementia. As dementia is viewed as normal ageing or subject to social stigma, help-seeking is low, and family carers (mainly daughters-in-law carry the responsibility (Dias & Patel 2009; Sharma & Bothra 2018).

Kumar et al. (2019) state the current situation for supporting people with dementia in India, highlighting the urgent need for action to improve the health and social care infrastructure. Improved access to diagnosis and treatment services, increased awareness of dementia and promotion of prevention strategies and reducing stigma related to dementia are areas of need. While there is increased attention on dementia through the promotion of a 'dementia friendly India' there is scant attention to the development of an integrated system of care. In 2010, the Alzheimer's and Related Disorders Society of India asserted that there was 'no structured training on the recognition and management of dementia at any level of the health service'. Services were described as insensitive, including not providing adequate information and support for family carers (Shaki et al., 2010). Das (2014) reported that dementia education for nurses, health care attendants and physicians within general hospital and primary health care settings in India was inadequate. Two small studies of dementia knowledge, one of medical staff and one of graduating nurses found that there a marked deficiency of knowledge about dementia. They recommended mandatory dementia education in medical and nursing education (Poreddi et al., 2015; Biswas et al. 2017). It is argued that all undergraduate geriatric, general medicine, and primary care workers require additional aspects of dementia care education to drive much-needed infrastructure developments (Das 2014).

Dementia is a progressive and terminal condition that gives rise to complex health and care needs associated with a deterioration in both brain and bodily health. In the early or mild stages of illness it is possible, to live independently and as the condition progresses to the moderate and more advanced stages dementia-related changes in the brain lead to recognisable symptoms and increasingly complex needs and levels of dependency. Reisburg et al. (2006) were among the first to describe the middle or moderate stages as the beginning of an extended, intensive palliative care phase or what others call the continuing care phase. It is beyond the scope of this paper to explore in depth the arguments and challenges of illness staging and dementia prognosticators, but important to acknowledge the contemporary debates and calls for both dementia specific palliation and dementia end of life care. The 2014 a European White Paper, which set out a progressive dementia palliative care model made an important contribution by bringing together and bridging the sometimes different perspectives from palliative care experts and dementia care experts (van der Steen et al 2014, 2016). Subsequently Hanson, et al. (2016) cautioned against equating dementia palliation to death and dying as people can live for years with advanced dementia palliative care needs. Accordingly, there have been calls to recognise a continuum of care needs associated with living the best life possible with advanced dementia or 'palliare' (equating to active palliation or continuing care), prior to transitioning to the final and end of life of phase of death and dying (Tolson et al. 2016). Contemporary interdisciplinary deliberations about the later stages of dementia in some countries such as Scotland, embrace the needs of both the recipients of care and family carers (Alzheimer Scotland, 2019). Macrae et al. (2019) are among those who embrace this new integrated positive dementia palliative care narrative and recommend a dementia-specific approach to palliation which requires expert know-how and skills.

There is a clear need to understand further the impact of dementia on families, as well as a need to develop education solutions to support health and social care professionals to work with families experiencing dementia. This research aims to gain insight of the experiences and challenges facing family carers of people living with advanced dementia in India to understand education needs of family carers in relation to dementia specific palliation and to help inform the development of practitioner education and integrated services.

Methodology

Three facilitated community conversations with family carers of people with advanced dementia were carried out using a focus group methodology in South India. One of these

focus groups was conducted in English within the local town and the other two were carried out in the local language (Kannada) in local villages. The focus groups in Kannada were facilitated by a bilingual member of the research team with prior ethical clearance.

Ethical approval for the project was secured 13/3/19 from the Kasturba Medical College and Kasturba Hospital Institutional Ethics Committee (Reference IES 220/2019) and endorsed by UWS School of Health and Life Science Ethics Committee. The project also obtained Clinical Trials Registry-India registration (# CTRI/2019/04/018807).

Recruitment

There were two methods of recruitment for the focus groups. Recruitment for the English language focus group used a snowball sampling approach using existing networks within the local university. Information about the study was distributed through the University network and staff members and students contacted the local research team for information before consenting to participate. The inclusion criteria for the English language focus group were:

- Fluent in English
- Currently caring for a family member with advanced dementia
- Able to attend a focus group on the local university campus at a specified time

Recruitment for the local language focus groups was facilitated by a local medical team who held treatment camps in local community centres. Members of the research team attended one of these camps approximately two weeks before the focus group to provide information about the study. Participants were provided with study information and potential participants were able to ask questions about the research and what would be required of them. They were then given the date of the focus groups to attend if they wished to participate. Inclusion criteria for the local language focus groups:

- Currently caring for a family member with advanced dementia
- Able to attend focus group at a specified venue within the community at the specified time.

A focus group schedule was collaboratively developed by the research team and explored current care experiences, family situations, support networks and views of caring, safety and security of family carers. All focus groups were audio-recorded, transcribed and translated to English (where required). Focus group 1 was facilitated by English-speaking members of the research team in English. Focus groups 2 and 3 were carried out in the local language (Kannada) were translated to English and back to Kannada by two bilingual members of the research team and also a bilingual health care professional who understood medical terminologies related to dementia.

Participants

Participants in the three focus groups were all involved in caring for a family member with dementia. All of the participants were carers for people of an older generation, parents, and grandparents. This included both biological parents and in-laws. Table 1 outlines the numbers of participants in each focus group.

[TABLE 1 ABOUT HERE]

Data analysis

Analysis of the focus groups was carried out using framework analysis (Ritchie & Spencer, 2002). An initial familiarisation of the data involved reading and re-reading the transcripts from focus groups 1 and 2 and listing, highlighting and noting the key ideas and themes in the data. This allowed the research team to develop an initial thematic framework from the data. The second stage was to index sections of the data, which are pertinent to each theme within the framework. The indexing stage was carried out by two members of the research team. Following this, data were charted, and final themes were agreed as described below.

Findings:

The analysis resulted in three interlinking themes, with subthemes as outlined in Figure 1. These three themes related to the care experiences of people with advanced dementia and their families. A fourth theme was also identified, which explores family carers awareness and views of training needs in advanced dementia.

[FIGURE 1 ABOUT HERE]

Conditions of caring

In understanding the experiences of family carers of people with advanced dementia, the focus group participants described a range of factors which shaped their care experience. The majority of focus group participants expressed concern about the level of physical disability their family member experienced as a result of their dementia. This included concerns related to the fundamental needs of the individuals, including eating and drinking, going to the toilet, washing and dressing.

He cannot go to the bathroom.....he cannot get up.... cannot walk.....and even cannot call. (P2, FG 2)

This meant that they required constant care and support throughout the day. Within the local culture, there is an expectation that family members are responsible for providing this care.

We are doing our duties and responsibility; if they are satisfied, we are also satisfied (P4, FG2)

Although the majority of participants were female, they explained the expectation on females to take on the primary care roles for family members living with advanced dementia. , the majority spoke of male relatives helping with some aspects of the care. However, it was clear there was a cultural expectation females should take on the caregiver role. For some, this meant that they had to sacrifice their ambitions and careers to take on the caregiver role.

I wanted to do PhD nursing, things went very good I was selected but I couldn't join the course my husband said that it is not possible for you to join the course either you have to sacrifice your PhD, or else we have to put my mother to the old age home. (P6, FG1)

Despite caregiving being viewed as a predominantly female role, there was an acknowledgement by the majority of participants that their male relatives were involved with the care of their family member and they helped out where possible. Additionally, there was a conflict between caring for older relatives with dementia and caring for children. Multi-generational households are traditional in Indian culture. Some of the participants, however, described and expressed concerns about a recent cultural shift to a nuclear family model where adult children move away from home leaving older parents living alone.

My husband and me both are working so suddenly if the caregivers leaves it becomes extremely difficult.....that is the major problem when the family is nuclear, if it is a joint family somebody will be there when we're urgently in need. (P9, FG1)

Although there are options to have paid care in the home, the participant expressed distrust around this.

They are not professional caregivers, they are like other helpers at home, someone who comes as on earning basis, they do not really understand towards the depth they have to take care or in what way they actually have to look at. (P1, FG1)

Additionally, the high costs of hiring paid carers make it difficult to sustain over time.

I asked many caregivers they charge around 15000-20000 rupees and all that also is very costly. Our salary that is staff nurse salary is around 14000 to 20000 then instead of that it is better unless and until I get a person who is cost effective for me it is better for me only to take care. (P6, FG1)

It should be noted that only the participants in focus group 1 discussed the potential use of professional caregivers. This may be due to the socio-economic status of the participants working in professional roles in the university, compared to those living in rural villages in focus groups 2 and 3. In contrast, the economic concerns of participants in focus groups 2 and 3 were around the fact that they had to leave their loved one alone while they went to work. Although it was acknowledged that this was potentially dangerous, there was no other option.

I have to get income, I have to work, even if it is dementia, I have to leave my mother and go to work. I mean, she is my mother, it's very difficult. I have to give her tiffin and then go.... she is very much dependent on me. (P5, FG2)

The final factors which influence the conditions of care are misconceptions and social stigma around dementia. These misconceptions are about the causes of dementia, the abilities and the care needs of a person with dementia. For example, participants in all focus groups expressed a belief that dementia is just a part of normal ageing:

I think as age advances everybody gets this type of problem so this is my thinking towards dementia. (P4, FG3)

This can prevent families from seeking medical advice or diagnosis. Particularly where there is a feeling that nothing can be done to help the person with dementia. The participants in focus group 1, who had some education in health care where aware of the need for medical support and diagnosis, however the explained how their families were often resistant to the idea. This was another contrast between the focus groups, as participants in focus groups 2 and 3 were reluctant to discuss the issue of diagnosis.

I had called all my family members and told that grandmother is in this stage and now it is a high time for us to go to the doctor. So fixed the appointment with the doctor; after I fixed the appointment with the doctor my family member did not talk to me. (P5, FG1)

Intersecting Vulnerabilities

The stories told by the participants showcase intersecting vulnerabilities in the participants' situations. The conditions of caring creates a vulnerability for the carers' physical and mental wellbeing. This in turn makes the person living with advanced dementia more vulnerable to the reactions of the caregiver, for example, the impacts on their ability to provide care.

As described above, the majority of care for people with advanced dementia is provided within the home and by family members. This creates vulnerabilities for both the family carer and the person with advanced dementia. The lack of external support for family carers increased the burden of care and associated stresses of trying to manage caring with other responsibilities putting them at increased risk of physical and mental illness. Many participants recognised these risks as a vulnerability of the caring role.

The caretaker also has the risk of going for depression.... and I was very much worried my sister in law that time and because of my job I couldn't take of my mother to my house. (P4, FG1)

Participants also spoke of the problem of lack of sleep, particularly where they are balancing caregiving duties with work, and other family responsibilities. A number of the participants spoke about the person with advanced dementia experiencing disturbed sleep which impacts on the wellbeing of the rest of the family.

Our children are also having difficulty in sleeping, even my father, even my husband, everybody we are all suffering because of that, because she screams very loudly during night time. (P5, FG1)

This in turn creates a vulnerability for the person with dementia who risks losing their care and support if their family member unable to provide care for reasons of ill-health.

One person cannot take care and the person who is taking care also will find it difficult task..... because one person cannot take care alone taking care will be very difficult for the person, she also will develop multiple illness. (P6, FG1)

The intersecting vulnerabilities identified from the focus groups puts both the family carer and the person with dementia at risk of poor health and wellbeing. The result of these vulnerabilities is discussed in the final theme below.

Desperate acts of care

Due to the care conditions and the resulting vulnerabilities, some of the care practices adopted by family members could be considered to be abusive, coercive or neglectful. Family carers acknowledged this when discussing these care practices. However, they expressed that they have no other choice than to cope with their situation and that they are the result of desperation.

We are family members we love them a lot; things can happen in such a way that it can render to abuse probably. (P1, FG1)

Examples of desperate acts of care relate to supporting family members with advanced dementia with the fundamentals of care; eating, drinking, washing and going to the toilet. There were examples spoken about where coercion was used to ensure that family members felt that they had provided care to their loved one before going to work or engaging in other tasks such as looking after children.

It is not like regularly we restrain when we are near here. We just leave her alone, when we ya... to use washroom, when we are away from home. We have no other way. (P5, FG1)

Additionally, participants spoke about the use of physical restraints to reduce risk and to ensure that their family member was safe. Examples such as tying a person with dementia to a chair on the porch or locking the bedroom to ensure they couldn't fall or wander off. Despite an awareness that these practices were potentially abusive, the participants spoke of having no other option due to the increasing burden of the caring and other responsibilities such as employment or childcare.

She will be sitting out in the veranda the whole time we have to put up the fan on for her, and it is too difficult my mom should monitor both the children and her we have to put cloth around her body we have to put it to the chair [so she doesn't fall] (P5, FG1)

Finally, several participants spoke of the isolating of the person with advanced dementia as a result of social stigma and cultural beliefs about dementia. Although beyond what would be considered the fundamentals of care, the lack of social support and separation of people with dementia described could have negative consequences for those experiencing it.

With this problem, you can't socialise and you can't have normal relationship with people around. (P2, FG1)

It is clear from the focus groups data that the experience of living with and caring for a relative with advanced dementia in Southern India produces a set of difficult challenges for families. Families often do not understand dementia and improvise the best they can to protect their family member with dementia. Only one participant in the three focus groups spoke explicitly about the end-of-life care for her relative with advanced dementia. She viewed her relative as in a stage now where she was suffering and there was little she could do to help her. As such, she viewed death as the only resolution to her suffering.

She is bed-bound to see this, bed sore and all this. We are now... I am praying for God to remove my mother in this situation.... It's terrible (P4, FG1)

Training needs for advanced dementia

Family carers, through their participation in the focus groups, explicitly and implicitly illuminated the need for education in advanced dementia and effective person-centred solutions to every day caring experiences. There was an assumption that employed home carers could not adequately care for their family members because they did not love the person and were only interested in picking their wages. Additionally, the lack of trust in home carers' abilities to look after a family member with dementia, stemmed from the assumption that they were untrained to support a person with complex needs. Participants articulated a feeling that only family members, who had reciprocal love and trust were able to provide support with the fundamental care required by family members with advanced dementia, failing to recognise the health needs of people with dementia.

With that we have to show a lot of love to these types of dementia patient. When we show them love automatically, they will start listening to us. (P3, FG3)

However, there was a recognition from some participants in the English language focus group that love was not enough. There was a clear need for training for family carers to be able to provide the specialist care required by a person with advanced dementia.

Even if we just love our dear ones, love cannot help all the times it needs special care. (P1, FG1)

Additionally (for some) the lack of awareness that advanced dementia is a complex condition which requires specialist skills and training to provide care and support for a family member creates a further vulnerability for both.

I think as age advances, everybody gets this type of problem, so this is my thinking towards dementia. (P4, FG3)

In contrast, the participants in the local language focus groups did not identify a training need to be able to provide specialised care. They felt, because they were caring for a loved one, they would do what was required to care to the best of their ability and did not want external involvement or training.

To give care to the patient, I don't think we need any extra training.....Suppose they have diabetes and hypertension, in that case, we require some knowledge otherwise, if there is only dementia and if we think about us too in that situation... we may be able to take better care of our loved ones. (P1, FG3)

I don't think training is required as we do not give any special care to the patient. (P8, FG3)

Discussion

The findings of the focus groups confirm that there is a lack of understanding of the needs of people with advanced dementia and the resulting palliative care needs, stemming from a lack of understanding of dementia. Apparent passive acceptance of difficult caregiving situations is fuelled by a lack of alternatives, and a combination of low expectations, cultural norms, and myths about ageing and senility. **This creates vulnerabilities for both the person with advanced dementia and the family carer, putting them** at risk of physical, financial and emotional hardships. These vulnerabilities combine and lead to acts of desperate care, which, although well intended, have the potential to be harmful or undermine the rights of people living with dementia.

These findings reveal the lack of confidence in paid carers and the often hidden desperation that can occur within family care. These are crucial considerations for those tasked with developing integrated care services in India. However, when interpreting these findings study limitations should be acknowledged. Although attempts were made to ensure that the views of carers from different experiences and backgrounds were represented, the majority of the data in this analysis was drawn from the English language focus group, **which was considerably longer. The English speaking participants were educated urban dwellers with more confidence to talk in an interview situation than the more rural and village-based local language participants. The caste system is predominant in local Indian cultures and may have influenced recruitment, therefore this should be taken into account in future studies to ensure all participants are enabled to engage equally.** Despite the differences in interview fluency, the experiences reported across groups were similar concerning caregiver burden, cultural expectations and stigma and the lack of formal support. The key difference is that the English speaking and arguably more professional group of caregivers saw a need for their dementia care training, compared to the local language, group who seemed resigned to make do as they had always done.

The stigma surrounding dementia means that rather than seeking medical support, families are more likely to carry the burden of care for their family member. **The most common family dynamic is the joint family, where adult children and their spouse/young children live with**

elderly parents, who may be are sick or requiring some form of care. Decisions are usually made by the head of the family (the eldest male) and when the elders develop dementia, it can be challenging to to address the issues surrounding diagnosis, medical care or palliative care. Therefore, because Indian families are male dominant families it usually falls to the daughters-in-law or the spouse to provide care. This is reflected in the demographic characteristics of the focus groups presented here and consistent with previous research (see, Srivastava, et al., 2016). High levels of care giver burden are reported throughout the literature, with emphasis on the disproportionate impact on females. This is expressed as an emotional burden as well as having consequences for their own physical and mental health (Narayan, et al., 2015; Grover et al., 2017). Narayan et al. (2015) found that caregivers frequently expressed difficulties in supporting their family member with dementia with the basic tasks of daily living, for example, eating and drinking, washing and going to the toilet. These tasks were made more challenging due to what they perceived as their relative's unpredictable and disruptive behaviours. The findings here confirms this experience and develops this to show that these difficulties can lead to caregivers adopting potential risky care practices, out of desperation which could result in unintentional abuse, abandonment or neglect of their relative. Another qualitative study carried out by Danivas et al. (2016) found family carers had similar concerns about their relative's safety in the home environment. The study found that family carers routinely used various coercive measures on their family member with dementia, including the use of psychotropic medicines, physical restraints, isolation, restriction of fluids and food and preventing access to finances. The coercive behaviours described by participants in this study could be viewed as a form of abuse which impinges on the individuals' human rights and liberties. Similar to our study, the participants themselves felt that they had been coerced into a situation of caregiving due to cultural and familial expectations, resulting in them viewing these care practices as their only option.

Several research studies have identified a lack of awareness and understanding of dementia in India among healthcare professionals (Danivas et al., 2016), family members and in society in general (Hossain et al., 2018). Brijnath (2011) identified that culturally, dementia is not viewed as a biological process or medical illness, but linked to cultural expectations of ageing (sathiyana or 'going sixtyish') or religious beliefs, where dementia is viewed as God's punishment (Hossain, et al. 2018). Interpreting the focus group results in this context, it is clear to see why, as a result, dementia is stigmatised and hidden within families and society. This can prevent families from pursuing a diagnosis and, unless they 'see' dementia as a clinical problem (Hossien et al. 2017). In the advanced stages of dementia, the health and clinical care needs of the person are clear. Although the participants in focus group 1 did acknowledge the healthcare needs, there was still a reticence to access formal support and an acknowledgement that even if they did, there was little support available. For the participants in focus groups 2 and 3, the evidence of the effects of stigma was clear. Participants did not feel that they required the support of education and that it was their duty to care for their loved one. This was further demonstrated by the participants' reluctance to talk in detail about their situation and their loved one. This may be reflective of the concept 'you don't know what you don't know' (White et al., 2018).

The role of caregiving is often so intense, and there is little time for reflection between tasks that carers adopt coping strategies to survive. Fragmented services and inadequate assessment of palliative care needs undoubtedly adds to the strain of caring for a person with advanced dementia. As of today, India doesn't have enough training centres for dementia nor chronic disease management for home based care (Dias & Patel, 2009). Palliative care is usually given in designated centres and hospitals but few facilities are available, even in cities (Khosla et al., 2012). The European White Paper advocates that dementia care is tailored to the progress of the condition for the person and that for family

carers bereavement support is included (van der Steen 2014). This highlights the need for careful planning of progressive integrated dementia care services in India that support both the recipient of care and family carers. There is no doubt that better education for practitioners is required (Danivas et al., 2016, Hanson et al. 2016) as well as educational interventions for family carers (Roopalekha 2010; Pattanayak, 2011; Narayan et al., 2015, Hanson et al. 2016). Additionally, for those working with family carers from similar cultural backgrounds the insights presented here can support practitioners working within integrated services in other countries to develop and adapt culturally-sensitive services.

The Palliare Best Practice Statement (BPS), presented as an interdisciplinary learning framework sets out what both practitioners and family carers need to know and why in relation to advanced dementia care (Tolson et al. 2017 Holmerova et al. 2016). This resource offers a helpful starting point to think about the education and support needs of family carers in India. The findings presented here help to identify gaps in knowledge and can be used in conjunction with the BPS by healthcare professionals to prepare for a guide conversations with family carers about approaches to care and support needs. Increased awareness of the rights of people living with dementia is guided by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and the Mental Health Act (India) (2017), and should be a priority for integration into education, practice and communities.

The WHO Global Dementia Plan (2017), recommendations from ARDSI (Shaji, et al., 2010), the lens provided by the Palliare BPS (Hanson et al 2016) and the findings shared in this paper provide a basis from which to create a vision for integrated dementia-specific palliative care in India. To succeed such a vision should be designed with the involvement of people who have lived experience of dementia and with sensitivity and compassion to all who find themselves facing 'desperate acts of care'.

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